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**Testimony in Support of the
Connecticut Home Care Program for the Disabled
Appropriations Committee Hearing – March 4, 2011**

Senator Harp, Representative Walker, and distinguished members of the Appropriations Committee,

None of us have a clue what will beset us in the years to come. Some of us are young and some of us are old. I, personally, have been privileged to live a very healthy life. My name is Susan Tukey, I'm from East Hartford, and I am friends with many who are living with multiple sclerosis – one being a very dear friend of 15 years who just recently lost his mother. She lived to 92 years of age – just to take care of him. We often talked about what would happen to “Tommy” when she died. I always reassured her she did not have to worry because as long as I am alive I would take care of him!

It is an insurmountable task being a caretaker and unless you have walked in these shoes it is hard to understand the sheer number of hours that it takes. The task for a 92-year-old was burdensome, but she never complained. Everything we do - sitting, standing, getting dressed, putting on socks and shoes, jumping into the car - are all taken for granted until movement and mobility are taken away. This is the current status of my friend, who has been blessed with help from Ampyra, a newly released MS medication. Even though he has improved, there is always the possibility of exacerbations which can rapidly undo any progress. This occurred in my friend when he became totally bedridden.

It was touch-and-go for a few days, after which he went to rehab. Once he regained a little strength he was allowed to come home in my vehicle rather than an ambulance. His recovery became swifter because he was in familiar surroundings in his home with Mom's love, cooking and helping him, even at the age of 92!

Now what will happen to this proud but fragile man who is only 52 years old? He definitely will need more outside help with the progression of this disease. Presently I do a variety of things to make his life easier. I water and plant flowers, prune shrubs, and make meals for him. I have also been giving him extended physical therapy to keep him more mobile. I have helped him when he has fallen and had to crawl, exhausted, to an area where he would try to right himself, helping him to turn himself around to reach his bars or banisters where he might be able to pull himself up. I have also given him help when he has lost control of himself, making sure he was clean and had clean clothes to put on.

Even though Ampyra has been his gift of life and movement, he still is very fragile. For those who do not have family, friends or an alternative drug to aid them in living independently there is a critical need for in-home health care.

I do not get paid; I do it out of love and devotion for my dear friend. He is not entitled to any Medicaid and presently pays nearly \$1100 a month to continue taking medication for his well-being. Fortunately he can maintain for now, until he can receive Medicare, but the stress created by such enormous amounts of money taken from disability can cause undue stress, which could lead to another exacerbation. Keep our loved ones as stress-free as possible, give us options for care, and vote to continue funding for the Connecticut Home Care Plan for the Disabled.

Thank you,
Susan Tukey